In spring 2019, the North Carolina Institute of Medicine, in partnership with agencies and organizations that provide care and advocacy around issues of palliative care, hospice care, aging, and long-term supports and services, convened the Task Force on Serious Illness Care.

This task force included over 60 experts across many areas relevant to serious illness care, including health care providers (physicians, nurses, pharmacists, physician assistants), other members of serious illness care teams (including social workers and spiritual leaders), community advocates, veterans advocates, private and public payers, legal and financial planning experts, family and community caregiver representatives, health educators, and researchers. The NCIOM and partner agencies made diversity of expertise, experience, and geographic region of the state a key priority for membership. The NCIOM task force model allowed for wide, multi-disciplinary stakeholder engagement, enabled robust discussion, and led to a comprehensive and cohesive plan to address and improve serious illness care in North Carolina.

A steering committee contributed to developing the goals and scope of the task force work, selecting the meeting agendas and speakers, and developing dissemination and communications strategies. Jonathan Fischer, MD, Assistant Professor, Duke University Department of Community Health and Family Medicine; Joyce Massey-Smith, Director, Division of Aging and Adult Services, North Carolina Department of Health and Human Services; and Paulette Dillard, PhD, President, Shaw University chaired the task force.

The task force met 10 times in 2019 and 2020 to develop consensus-based, evidence-based, and actionable recommendations to improve serious illness care in North Carolina. The report of the task force provides policymakers, health providers and systems, and other stakeholders with a common vision and action steps to address the impacts of serious illness on North Carolinians.

TASK FORCE ON SERIOUS ILLNESS CARE: VISION STATEMENT

Through the course of the task force work, NCIOM staff guided members through the development of a vision statement that captured the scope and breadth of the areas of serious illness care prioritized for improvement.

Vision Statement: Our vision for serious illness care in North Carolina is a system and culture that prioritizes quality of living for people with serious illness, their families, and their communities. This system and culture will incorporate the following elements to achieve this priority:

- Health system and social change to address serious illness care
- High-quality person-centered care
- Engaging with patients and families to meet goals of care
- Development of the health and human services workforce and infrastructure to support serious illness care

ORGANIZATION OF THIS REPORT

This report is structured to address each of the priorities listed above and to provide context and background to support the recommendations of the task force. The recommendations enhance current work being done in the state and aim to build upon this work to meet the vision of the task force. The task force has identified appropriate stakeholder organizations to implement each recommendation.

The report contains an Executive Summary followed by the following chapters:

Chapter One: Introduction and Overview of Serious Illness Care

Chapter Two: Health System and Social Change to Address Serious Illness Care

Chapter Three: High-Quality Person-Centered Care

Chapter Four: Engagement with Patients and Families to Meet Goals of Care

Chapter Five: Development of the Health and Human Services Workforce and Infrastructure

Chapter Six: Conclusion

Appendices

WHAT IS “SERIOUS ILLNESS”?

Serious illness occurs when chronic or acute health conditions become serious enough to affect a person’s general health and functioning, and the illness is potentially life-threatening. For individuals with serious illness, it is possible that the effectiveness of curative treatment will decrease, and the focus of care may shift toward comfort. Throughout the work of the Task Force on Serious Illness Care, the task force used the above definition of “serious illness,” as well as the additional context that the task force scope was defined by individuals for whom a health care provider would not be surprised if they were to die in the next year.

SERIOUS ILLNESS IN NORTH CAROLINA: DEMOGRAPHICS

According to U.S. Census Bureau estimates, 16.3% of North Carolinians, or about 1.7 million people, are over the age of 65.[1] The over-65 population of North Carolina is projected to increase 67% between 2016 and 2036, from 1.6 million to 2.6 million people.[2]

While serious illness is not solely an issue for older adults, rates are higher in this population. The 2018 Behavioral Risk Factor Surveillance Survey (BRFSS) reported that 65.8% of respondents aged 65 and over had two or more chronic health conditions[a], and an additional 31.3% of respondents aged 65 and over had one chronic health condition.[3]

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[a] *Includes heart disease (heart attack/stoke/angina), current asthma, skin cancer, other cancer, COPD, arthritis, depression, kidney disease, and diabetes. Note: Not all of the reported chronic health conditions would necessarily fall into the definition of serious illness used by the task force.*

FIGURE 1.1 Leading Causes of Death in North Carolina, 2017

	DEATHS	RATE	STATE RANK	US RATE
1. Cancer	19,474	157.1	21st	152.5
2. Heart Disease	18,808	156.5	27th	165.0
3. Accidents	5,985	56.3	20th	49.4
4. Chronic Lower Respiratory Diseases	5,540	45.3	23rd (tie)	40.9
5. Stroke	5,098	43.0	10th	37.6
6. Alzheimer's Disease	4,289	37.3	13th	31.0
7. Diabetes	2,903	23.6	17th	21.5
8. Flu/Pneumonia	2,076	17.5	11th (tie)	14.3
9. Kidney Disease	2,040	17.0	9th	13.0
10. Suicide	1,521	14.3	35th	14.0

Source: CDC National Center for Health Statistics; 2017. https://www.cdc.gov/nchs/pressroom/states/northcarolina/northcarolina.htm

In North Carolina, the number of individuals with serious illness is expected to rise as the population ages. In 2009, the North Carolina State Center for Health Statistics projected 46,417 new cancer cases for that year (and 18,277 deaths). For 2019, the number of projected new cancer cases was 62,466 (and 21,426 projected cancer deaths).[4]

Rates of heart disease have also been rising. According to the BRFSS, in 2012, 4.5% of adults reported being told by a health professional that they had angina or coronary heart disease. In 2019, 5.7% of adults reported this diagnosis. Among adults over 65, 15.9% reported being diagnosed with heart disease.[5]

While acknowledging that much of the task force's work focused on older adults, the task force also examined particular needs (and cross-cutting needs) of younger adults and children with serious illness. In 2010, the most recent year for which data is available on a survey module for children with special health care needs, 12.9% of respondents to the statewide Child Health Assessment and Monitoring Program survey answered that their child "currently needs or uses more medical care, mental health or educational services than is usual for most children of the same age." In the same survey, 6.1% of respondents said that their child was "limited or prevented in any way in his/her ability to do the things

FIGURE 1.2 Projected Rates of Serious Illness, By Condition

	ACTUAL RATE (2018)	2019-2020 PROJECTED	2030 PROJECTED
Alzheimer's Disease	P: 170,000[b] persons 65+	180,000 (2020)	210,000 (2025)
Cancer[c]	I: 52,752 (2017) IR: 423.9 per 100K (NC Registry)[d] I: 55,394 (2016) IR: 458.4 per 100k people (age adjusted)[e] (CDC)	Projected incidence: 62,466[f] (NC Registry)	In 2017, the North Carolina Prevention and Control Branch: NC Comprehensive Cancer Control Program stated that the incidence rate was on the decline—decreasing 9.4% from 2009 to 2014.[g]
Diabetes	P: 12.5%[h] (crude) 2019 P: 11%		Projected to be rising nationwide, especially among adults aged 65 and older.[j]
Heart Disease	Heart attack: 5.4%[k] Angina or CHD: 5.7%[l]		
Kidney Disease	P: 3.2%[m] (crude)		Between 2015 and 2030, prevalence of end stage renal disease (ESRD) is projected to rise 19-39% for adults 45-64 years old, 23-75% for those aged 65-74, and 4-51% for adults over 75.[n]
Respiratory Illness	P: 8.1%[o]		
Stroke	P: 3.8%[p]		

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[b] *Alzheimer's Association, 2018. https://www.alz.org/media/documents/northcarolina-alzheimers-facts-figures-2018.pdf*

[c] *This data excludes cervical carcinoma and basal and squamous cell carcinomas of the skin. North Carolina State Center for Health Statistics. https://schs.dph.ncdhhs.gov/units/ccr/*

[d] *North Carolina State Center for Health Statistics https://schs.dph.ncdhhs.gov/schs/CCR/incidence/2017/racegender_v2.pdf*

[e] *Centers for Disease Control and Prevention. United States Cancer Statistics https://gis.cdc.gov/cancer/USCS/DataViz.html*

[f] *North Carolina State Center for Health Statistics https://schs.dph.ncdhhs.gov/schs/CCR/proj19co.pdf*

[g] *NC Department of Health and Human Services. North Carolina Cancer Prevention and Control Branch. https://publichealth.nc.gov/chronicdiseaseandinjury/cancerpreventionandcontrol/docs/ReducingtheBurdenofCancerResourceGuide.pdf*

[h] *Centers for Disease Control and Prevention. BRFSS Prevalence and Trends Data, 2018.*

[i] *County Health Rankings 2019*

[j] *Lin J, Thompson TJ, Cheng YJ, Zhuo X, Zhang P, Gregg E, Rolka DB. (2018) Projection of the future diabetes burden in the United States through 2060. Population Health Metrics, 16(9). https://pophealthmetrics.biomedcentral.com/articles/10.1186/s12963-018-0166-4*

[k] *North Carolina State Center for Health Statistics https://schs.dph.ncdhhs.gov/data/brfss/2018/nc/risk/CVDINFR4.html*

[l] *North Carolina State Center for Health Statistics https://schs.dph.ncdhhs.gov/data/brfss/2018/nc/risk/CVDCRHD4.html*

[m] *Centers for Disease Control and Prevention. BRFSS Prevalence and Trends Data. Kidney Disease. 2018.*

[n] *McCullough KP, Morgenstern H, Saran R, Herman WH, Robinson BM. (2019). Projecting ESRD Incidence and Prevalance in the United States through 2030. J Am Soc Nephrol 30: 1-9. https://jasn.asnjournals.org/content/jnephrol/early/2018/12/13/ASN.2018050531.full.pdf. The prevalence of those under 45 years of age is projected to move in both directions, decreasing as much as 2% and increasing as much as 7% from its 2015 values.*

[o] *North Carolina State Center for Health Statistics. 2018. https://schs.dph.ncdhhs.gov/data/brfss/2018/nc/risk/CHCCOPD1.html*

[p] *North Carolina State Center for Health Statistics. 2018. https://schs.dph.ncdhhs.gov/data/brfss/2018/nc/risk/CVDSTRK3.html*

most children of the same age do."[6] In addition, in North Carolina, there were 4,834 cases of pediatric cancer between 2003 and 2014, at a rate of 162 cases per 1 million population, one of the higher rates in the country. Overall, pediatric cancer rates are highest among children aged 0-4 and teens aged 15-19, as compared to children aged 5-14.[7]

FIGURE 1.3 Serious Illness Rates by Disease for Children and Young Adults (0-19 years of age), U.S

Cancer (all types)	161.0-171.4 per 1,000,000 (2018-2019 age-adjusted cancer incidence rates)
Cystic Fibrosis	25 cases per 100,000 (2017 Newborn Screening)
HIV/AIDS	0-13 years old: 4.9 per 100,000 (2018) 13-14 years old: 9.5 per 100,000 (2018) 15-19 years old: 24 per 100,000 (2018)
Congenital Heart Disease	131 cases per 100,000 (2017 Newborn Screening)

Sources: Cancer: https://www.cdc.gov/cancer/dcpc/research/articles/rates-children-teens-state-region.htm
Cystic Fibrosis: http://www.ncmedicaljournal.com/content/80/1/45/T1/graphic-1.large.jpg
HIV/AIDS: https://epi.dph.ncdhhs.gov/cd/stds/figures/hiv18rpt_02042020.pdf
Congenital Heart Disease: http://www.ncmedicaljournal.com/content/80/1/45/T1/graphic-1.large.jpg

HEALTH SYSTEM AND CULTURE CHANGE TO SUPPORT SERIOUS ILLNESS CARE

The Task Force on Serious Illness Care recognized that, with rising rates of many serious and chronic conditions in our state, it is crucially important to develop a system and culture that aims to improve the quality of living for individuals with serious illness, their families, and their communities. The Task Force on Serious Illness Care built recommendations using the previous and ongoing work of many experts throughout the state and nationally. In addition, the task force recognized the need for ongoing collaboration and governance to ensure implementation of the task force recommendations.

In addition, the task force examined the need for broader cultural and systemic changes needed to address the challenges faced by individuals with serious illness. Throughout the development of the recommendations, the task force was guided by principles of health equity, with a special consideration for the disparate impacts of serious illness among vulnerable populations, both in rates of specific conditions as well as in access to services and experience of receiving care. As the health system, and communities more broadly, address disparities in care, they must also keep cultural competency in mind. Cultural competence, in the health care context, is defined as "behaviors, attitudes, and policies that come together in a system, agency, or among professionals that enables effective work in cross-cultural situations."[8] The task force examined the ways that cultural factors such as customs, values, and institutions of racial, ethnic, religious, or social groups may impact the delivery of serious illness care, advance care planning, and engaging with patients and families, and worked to ensure that the recommendations reflect these considerations.

HEALTH EQUITY is the absence of avoidable or remediable differences, allowing for the attainment of optimal health for all people. Health equity is achieved when everyone has the opportunity to attain their full health potential and no one is disadvantaged because of socially determined circumstances. Achieving it requires focused and ongoing societal efforts to address avoidable inequalities, historical and contemporary injustices, and the elimination of health and health care disparities.

Source: Racial and Ethnic Health Disparities in North Carolina: North Carolina Health Equity Report, 2019. NC Department of Health and Human Services.

HIGH-QUALITY PERSON-CENTERED CARE

Recommendations in Chapter Three address improvements in care for individuals with serious illness, including care delivery and coordination, financing/payment for serious illness care, and addressing non-clinical needs.

LONG-TERM SERVICES AND SUPPORTS

Among all adults aged 65 and over, it is estimated that around half will develop an illness serious enough to need long-term services and supports. About one in seven adults over 65 will need these services for longer than five years. There are a broad range of long-term services and supports, which provide varying levels of medical care and non-medical care, including assistance with activities of daily living. Long-term services and supports can be provided in the home, in a community setting, or in a designated residential care facility. Due to the range of types and locations of long-term services and supports, there is also a range of payment systems for these different types of care.

LONG-TERM SERVICES AND SUPPORTS include a wide range of paid and unpaid medical and personal care assistance that people may need—over many weeks, months, or years—when they have difficulty completing self-care tasks as a result of aging, chronic illness, or disability. These services can be provided at home, in a community setting, or in an institutional setting such as a nursing home or assisted living.

PALLIATIVE CARE AND HOSPICE CARE

Throughout the work of the Task Force on Serious Illness Care, members discussed palliative care, hospice care, and the similarities and differences between the two, as well as misconceptions about when and how palliative and hospice care are delivered.

Palliative care is a type of specialty care provided to individuals living with serious illness. Palliative care focuses on providing relief from symptoms, increasing comfort, and improving quality of life for individuals and their families. Palliative care includes clinical care, such as symptom management, expert communication about disease trajectory and what to expect, and coordination of care across health care providers and settings.[9] Hospice care, like palliative care, also focuses on providing comfort, relieving symptoms, coordinating care, and improving quality of living for people with serious illness. Unlike with palliative care, however, in hospice care curative treatments are stopped. Hospice care is for individuals nearing the end of life, usually for those expected to live for less than six months, though hospice can be provided for any individual with a life-limiting illness.[10] For pediatric patients, the inclusion criteria is different: patients do not have to stop curative treatment while receiving hospice care.[11]

FIGURE 1.4 Distinctions Between Hospice and Palliative Care

	PALLIATIVE CARE	HOSPICE
Model of care	Interprofessional collaborative practice teams, including physicians, nurses, social workers, chaplains, care mangers; primary goal is improved quality of life	Interprofessional collaborative practice teams, including physicians, nurses, social workers, chaplains, care mangers, and volunteers; primary goal is improved quality of life and relief of suffering
Eligibility	Any age and with any diagnosis or stage of illness; can be delivered concurrently with life-prolonging and disease-directed treatments	All ages with prognosis of less than six months to live, must forgo Medicare coverage for curative and other treatments
Place	Hospitals, clinics, group practices, home settings, skilled nursing facilities	Home, long-term care facilities including nursing homes and assisted living, residential hospice facilities or inpatient hospice units
Payment	Doctor and nurse practitioner fees covered by Medicare part B for inpatient or outpatient care; hospital care covered by Medicare part A or commercial insurance; flexible bundled payments under Medicare Advantage, managed Medicaid, ACOs, other commercial payers	Medicare hospice benefit; commercial insurance usually modeled after Medicare; Medicaid. Medication costs included for drugs related to primary illness.

Source: Kelley AS, Morrison RS. Palliative care for the seriously ill, N Engl J Med 2015; 373:747-755. https://www.nejm.org/doi/full/10.1056/NEJMra1404684;

Both palliative care and hospice care utilize a team-based model of care, in which medical staff, including physicians, nurses, certified nursing assistants (CNAs), and non-medical staff such as social workers, chaplains/faith leaders, therapists, and volunteers, work to meet individuals' and families' needs. The recognition of the individual and their family as integral members of the care team is of particular importance in team-based care for individuals with serious illness as well.

The number of innovative models for paying for specific types of care for individuals with serious illness is increasing. As described above, both Medicare and Medicaid have specific payment models to cover hospice care, with similar covered services. Please see Chapter Three for additional discussion of payment structure and recommendations to improve reimbursement for high-value serious illness care.

DRIVERS OF HEALTH

The Task Force on Serious Illness Care recognized the need for individuals with serious illness to receive services beyond clinical care. Clinical factors only account for around 20% of health outcomes. For individuals with serious illness, access to clinical services is crucial, but social, behavioral, and economic factors such as safe communities, housing, transportation, access to healthy food, education, and health behaviors also impact quality of living. These factors are called drivers of health (also known as social determinants of health). While most traditional clinical health care settings and stakeholders are not designed to address the non-clinical drivers of health, the task force examined ways to improve access to non-clinical services and the impact this will have on individuals with serious illness.

ENGAGING WITH PATIENTS AND FAMILIES TO MEET GOALS OF CARE

The Task Force on Serious Illness Care identified several important aspects to ensure that individuals are able to identify and achieve their goals for care, including meeting the principles of patient and family engagement, improving the processes and understanding of advance care planning, and creating a system that supports family and communities as they care for those with serious illness.

PATIENT AND FAMILY ENGAGEMENT

The core of patient and family engagement lies in welcoming the patient and family,[q] as well as non-family support systems, as important partners in care. The Institute of Medicine of the National Academies (IOM) describes patient and family engagement as a partnership among practitioners, patients, and their families (when appropriate) to ensure that decisions respect patients' wants, needs, and preferences. The IOM further states that patients should receive the education and support that they need to make decisions and participate in their own care.[12] For patient and family engagement to work, patients must have, or be given, the knowledge, skills, and confidence to manage their health and health care.[13] In addition, health care at every level needs to be patient and family centered. The Institute for Patient- and Family-Centered Care defines patient- and family-centered care as "an approach to the planning, delivery, and evaluation of health care that is grounded in mutually beneficial partnerships among health care providers, patients, and families."[14] The institute describes the foundations for patient and family engagement as dignity, respect, information sharing, participation, and collaboration. For individuals with serious illness in particular, increased engagement in care can address anxiety about care and disease trajectory and help individuals identify the values most important to them as they consider treatment preferences and goals.[15]

WHAT IS ADVANCE CARE PLANNING? "Advance care planning is about planning for the 'what ifs' that may occur across the entire lifespan. Advance care plans can be developed at any time, whether you are sick or well. Once you are sick and disabled with a progressive illness that will last until death, you really need a comprehensive care plan that considers your social supports, your preferences, and your likely course. Advance care planning is an essential part of such a plan." — *Joanne Lynn, MD, Center for Elder Care and Advanced Illness*

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[q] *In general, when "family" is referred to throughout this report, this includes non-relative members of an individual's personal support system, and the task force agrees that "family" should be defined by the individual.*

ADVANCE CARE PLANNING

In order to address the ways that individuals and families can best identify their goals of care and ensure that values for care and end of life are reflected in these goals, the task force examined processes and systems for advance care planning, including within the health system, the financial/legal system, and professional training.

Broadly defined, advance care planning is a process by which individuals can discuss and document their care preferences, "to ensure that health care treatment (they) may receive is consistent with wishes and preferences should (the individual) be unable to make decisions or speak" for themselves.[16] While the task force focused much of its work on advance care planning as related to people who have already been diagnosed with or are living with a serious illness, its recommendations also recognize the importance of advance care planning as a process across the lifespan, with many relevant stakeholders both within and outside of the health care system.

CAREGIVER: Throughout the task force process and in the text of the report, "caregiver" is used to refer to unpaid individuals, often family or friends but also volunteers, who provide care for an individual with serious illness.

SUPPORTING CAREGIVERS OF INDIVIDUALS WITH SERIOUS ILLNESS

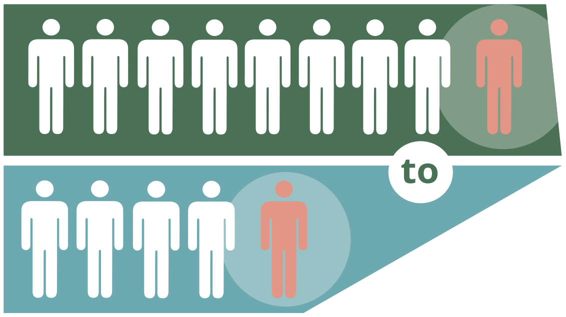
Individuals with serious illness often require increasingly intensive care as their disease progresses. Adult children and spouses are often the primary caregivers for adults with serious illness, with parents and grandparents usually the primary caregivers for children with serious illness. According to the North Carolina Department of Health and Human Services, nearly one-quarter of adults in North Carolina provide regular care or support to an older adult with a long-term illness or disability.[17] Of these caregivers, more than half are also employed full or part time. As the needs associated with serious illness increase, caregivers must often take time off work, hire additional help, and sometimes seek a care setting that offers round-the-clock skilled care. Seventy percent of caregivers have had to adjust work schedules to accommodate the needs of their loved ones. Caregivers experience high incidences of stress, anxiety, and depression and are more likely to incur higher medical costs themselves.[18]

Currently in North Carolina, the ratio of potential caregivers—people aged 45-64—to those over the age of 80 is eight to one. By 2030, there will only be four potential caregivers for every older adult in the state. For illnesses that require high levels of care, the declining ratio of potential caregivers to ill individuals may mean that nursing homes and other residential care facilities will play an increasingly large role in caring for those with serious illness.

Chapter Four examines additional aspects of patient and family engagement, advance care planning, and supporting family caregivers to improve care for individuals with serious illness.

The ratio of potential caregivers for each older adult in the state* will sharply decline from

8.0 in 2010



3.9 in 2030

As the caregiver ratio declines, there will be a larger financial, emotional, and logistical burden on individuals and families

*number of potential caregivers are 45-64 for each person 80 or older

Carrie is a live-in caregiver for her 83-year-old great-aunt Mary. Mary is a retired postal worker who was independent well into her 70s, but started needing some extra help around the house after a fall a few years ago. After Carrie moved in, she and Mary would run errands together every week, and would often take flowers from Mary's garden to neighbors and other friends of Mary's. In the last few months, Carrie has noticed that her aunt has not wanted to go out as often and has stopped working in her garden. Mary has also lost a fair amount of weight and has not been eating much. Carrie has contacted Mary's doctor, but Mary has been resistant to going to appointments, and has also refused to drink the nutritional supplements that the doctor has recommended. Carrie worries that Mary may be depressed or in pain, and is at a loss of what to do. She knows that she could force Mary to go to appointments, but really does not want to make her do anything she does not wish to do.

DEVELOPMENT OF THE HEALTH AND HUMAN SERVICES WORKFORCE AND INFRASTRUCTURE TO SUPPORT SERIOUS ILLNESS CARE

The Task Force on Serious Illness Care also focused on enhancing the health and human services infrastructure and workforce that delivers care to individuals with serious illness.

WORKFORCE TRAINING & INNOVATIVE WORKFORCE MODELS

As the number of Americans with serious illness increases as the population ages, an adequately trained health care workforce is critical to ensure that those with serious illness receive high-quality care.[19] With seriously ill patients often receiving care from multiple providers across different settings, team-based interprofessional collaborative practice is essential in providing for care coordination.[20] A strong interprofessional collaborative team should not only consist of physicians and nurses, but also include various others such as social workers, members of the faith community, care managers, patient managers, and community managers to ensure not only are the patient's clinical needs met, but their psycho-social needs are as well. Despite the importance of interprofessional collaborative teams in serious illness care, health professionals, community, and faith-based care managers need further interprofessional education training to ensure a team approach to patient-centered care.[21] To promote the development, training, and sustainability of interdisciplinary teams in serious illness care, the task force developed recommendations on promoting and implementing interdisciplinary trainings models. The task force also examined ways to promote training in serious illness care among primary care providers and geriatric and gerontology specialists.

In addition to training the health care workforce, the task force looked at different innovative workforce models in order to increase access to serious illness care in community-based settings. The community-based workforce models the task force examined included community paramedicine and community health worker programs. Both models are focused on providing high-quality care to patients in their communities and often in their homes.

ADDITIONAL INFRASTRUCTURE

In order to improve access to and quality of care for individuals with serious illnesses, the task force developed recommendations for building serious illness care infrastructure through the enhancement of health care provider and system interoperability and the usage of new care delivery technologies such as telehealth services. The task force focused on these areas to improve care coordination and communication capabilities among providers and/or systems, and access to care for the seriously ill in their own homes and communities.

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